HDSA
Huntington's Disease Society of America
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PHYSIOTHERAPY FOR HUNTINGTON'S DISEASE PATIENTS

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Physiotherapy is administered both in small groups and on an individual basis. Patients are assessed, then an individual treatment program is planned. Most patients respond particularly well to one-on-one treatment. Due to this emphasis on individual therapy, a high staff and volunteer/patient ratio is needed. Patients may attend P/T programs between 1 and 4 times a week.

Five of the 13 outpatients attending physiotherapy at the Arthur Preston Center in Australia are 'newly diagnosed'. These patients are in separate programs and have no physical contact with the more severely affected. As they become ready, they will be gradually integrated into the mainstream of the center. This, we feel, cannot be rushed.

AIMS OF TREATMENT -- NEWLY DIAGNOSED

1. To assess
2. To improve lung function, including lung capacity, and the abilities to exhale air, hold the breath, cough and nose-breathe
3. To teach relaxation techniques
4. To strengthen muscle groups, in particular:
   - o neck and back extensors
   - o shoulder girdle
   - o pelvic girdle -- stressing hip extensors and abductors
5. To reinforce and/or improve equilibrium reactions and righting reactions
6. To reinforce and/or improve gait patterns
7. To reinforce and/or improve perceptual skills
8. To improve endurance

We also aim to provide an environment where people newly diagnosed and their families can come together to talk -- not only to one another, but also to a variety of professionals (physiotherapists, occupational therapists, speech therapists and social workers). The different techniques used are based to a large extent on "Bobath" techniques of neurodevelopmental therapy.

AIMS -- PATIENTS WITH MORE ADVANCED HD

1. To assess
2. To maintain and/or improve lung function
3. To teach relaxation techniques
4. To maintain full range of movement, and prevent contractures in the long term
5. To strengthen muscle groups as needed
6. To facilitate more normal movement patterns
7. To improve gait, our aim being to keep patients mobile for as long as possible
8. To reinforce and/or improve perceptual skills
9. To improve balance and postural control
10. To maintain some hand function in order to encourage some degree of independence (e.g., dressing, feeding, toilet) for as long as possible
11. If necessary, to assist with the healing of pressure areas (rarely occurs)

TREATMENT PROGRAM

1. CREATIVE MOVEMENT

One of our physiotherapists is a specialist in creative movement. A trial program in the use of creative movement for HD patients has been completed. The results indicated that while this is a relatively new area of physiotherapy, it has an important application in the treatment of HD patients.

Creative movement involves the total person (physically, emotionally, socially, and intellectually) and aims to provide participants with an enjoyable and fulfilling experience involving self-expression and sharing within a small group (6-8 people) by non-verbal communication, combined with physical exercise. Physically, creative movement is able to strengthen muscle groups, stretch muscles, mobilize joints, and improve balance, coordination, and perceptual skills. Various properties are used, such as fabric, scarves, ribbon sticks, elastic, hoops, feathers and music. These provide a focus for the movement experiences.

Example of a Creative Movement Group

The group consists of approximately 8 patients and a high staff/patient ratio in order for the patients to achieve maximum benefit from the session.

The session begins with warm-up activities, such as:

- Rubbing all parts of body (promotes body awareness, coordination, muscle strength, and balance)
- Clapping hands together in different directions in space or onto different parts of the body (promotes body awareness, perceptual skills, symmetry, coordination, muscle strength, and balance)

The session proceeds to include not only group work, but also partner directed activities, in which participants share properties such as elastic, hoops, and fabric.

Activities make use of many different positions (e.g., sitting, lying, kneeling), depending upon the capabilities of the group. Sessions conclude with relaxation to music.

The length of the session is approximately 50 minutes.

Many HD patients experience perceptual problems. Some patients have decreased body awareness, while others have difficulty recognizing different directions in space (up, down, in, out). Perceptual defects may lead to difficulties with functions such as dressing, knowing which direction to take, negotiating obstacles, and judging distances. In this area, creative movement has great value. Not only can it help patients explore the space around them, it can also help them recognize different directions in space, and improve body awareness, making activities such as dressing easier.

Patients with perceptual problems respond well to repetition of an activity, which can often improve a patient's functional level. It is better to get these patients to do one thing over and over than to introduce different activities which may cause confusion. We have also been getting patients involved in activities such as fitting shapes into holes, forming cirles with shapes, and picture sorting (linking up visual perception with motor performance).

2. CHEST PHYSIOTHERAPY

During our initial assessments, we found that many patients had very poor lung capacity (Vital Capacity), and poor ability to blow, exhale and hold their breath. Many were breathing through the mouth rather than the nose, and had very erratic breathing patterns, inhaling air only as needed, sniffing or gulping it in, and using accessory breathing muscles in preference to the diaphragm. In practical terms, this meant they were probably more susceptible to:

- Chest infections
- Decreased endurance
- Added difficulty with speech, as we normally speak on exhalation
- Added difficulty with eating and swallowing, as we nose-breathe while eating and swallowing
- Difficulty coughing -- to cough effectively it is necessary to hold the breath, then exhale forcefully.

Treatment

- Postural drainage with vibrations and percussion in order to facilitate proprioception, to help eliminate secretions and to promote coughing

- Traditional breathing exercises have minimal value. Techniques incorporating a medium (e.g., blowing a tissue or a balloon along a feather) are of more value. Combining breathing with relaxation is very valuable as many patients' breathing patterns become more coordinated and deeper when relaxed.

Example

- Patient relaxes, keeps lips together and breathes through the nose in order to encourage nasal breathing and swallowing, and to encourage active closing of the lips.

- Patient relaxes and breathes in. On exhalation, the therapist gives compression to the chest wall for proprioception and to encourage vocalization on the outward breath.

3. RELAXATION/TOUCH THERAPY

Relaxation has become a more and more important part of our treatment program. We have found that by incorporating into our program techniques such as general relaxation, rhythmical massage, rhythmical passive and/or assist-active movements, there can be:

- Improvement in the ability to perform voluntary movements
- Decreased rigidity
- Release of anxiety
- Decreased involuntary movements
- A deeper, more coordintated breathing pattern, resulting in greater air entry with less effort.

Relaxation needs to be done on an individual basis or in very small groups with a high staff/patient ratio. Facial massage, in particular, can have quite dramatic results.

Example

Patient A had a very rigid face with facial muscles drawn up. In addition to its affect on his appearance, this made swallowing and speech very difficult, as it was almost impossible for him to voluntarily bring his lips together. He was also dribbling continuously. His treatment program stressed relaxation, face massage and gentle stretching of the facial muscles, followed by active closing of the lips, while encouraging nasal breathing and swallowing. This was done lying down (gravity eliminated), then later sitting up supported (against gravity), a more fuctional position. The patient is now able to voluntarily bring his lips together against gravity, can breathe through his nose without discomfort, and has some control over over his dribbling.